



Long Term Care Coordinating Council
State Plan for Alzheimer's and Related Disorders Working Group

Full Group Meeting

October 25, 2012

Run Time: 8:35 to 10:04

Casey Family Services

1268 Eddy Street

Providence, RI 02903

1. **Call to Order:** Catherine Taylor opened the meeting at 8:35 AM.
2. **Approval of Last Meeting's Minutes:** The minutes were approved unanimously.
3. **Sub-Group Reports:**
 - a. **Caregivers Subgroup**
 - i. Cathy McKeon reported that there has been one meeting so far in this subgroup and that minutes are going to be sent out soon.
 - ii. Currently, the Caregivers Subgroup is creating an overview of what support programs are currently available for caregivers across the state. In particular, it is looking at models for family support and respite care because it plans to study the gaps in this area. In Rhode Island, we are actively expanding respite care because there is federal funding available for related endeavors.
 - iii. The members of the sub-group have agreed that an expansion of the community support for families caring for the elderly is critical. They would like to look further into hospital-based resource centers and having trained volunteers to staff them in order to provide support.
 - b. **Workforce Subgroup**
 - i. Sarah Collins reported that there have been two meetings so far.
 - ii. The sub-group would like to focus on standardized training of the workforce that cares for the people with Alzheimer's Disease. These trainings would be for the workforce as a whole and would also include options specific to those within certain specialized fields (e.g. day care and long-term care). The members have spoken to URI's GEC and the Alzheimer's Association to see what programs are currently available.

- iii. The subgroup will be distributing a survey to care providers in the state. Currently, the survey is in its draft stage and it will be distributed to the full group.
- iv. Lt. Governor Roberts asked Sarah whether the workforce subgroup is looking to educate and train other types of caregivers such as ER and primary care givers. Sarah responded that this subgroup will try to categorize different levels of care to educate all levels of people who come into contact with people with Alzheimer's.
- v. Someone asked whether they were going to train the police force to deal with wanderers. Lindsay McAllister responded that they talked about that in the legal subgroup and hope to address it at a future meeting.

c. Access Subgroup

- i. Maureen Maigret was not present, but Lindsay McAllister provided an update. There has been one meeting. The group began by looking at transportation options and mobility challenges for those affected with Alzheimer's and dementia. Representatives from RIPTA and other EOHHS came to discuss disability transportation programs that are already in place. The subgroup has also identified funding sources and needs.
- ii. The subgroup also discussed the need to ensure safe driving for those with dementia. Dr. Ott, who has done research in this area, has been invited to speak to the subgroup for this reason.
- iii. Finally, the subgroup discussed the different ways in which preliminary screenings can occur through primary caregivers so that patients can be referred to dementia specialists.
- iv. Lt. Governor Roberts mentioned that in New York, there was collaboration between Wired Magazine and other organizations to discuss the intersection of technology and healthcare. There are initiatives now out to put sensors on home appliances to track whether people are developing dementia. These are examples of new ways in which caregivers can detect dementia before an emergency.

d. Long-Term Care Subgroup

- i. Rick Gamache reported that the first meeting had over a dozen attendees. There were representatives present from home caregivers, nursing, and adult daycare. The focus of this subgroup is to improve care in facility-based residential care. One of the core goals is to ensure that those with dementia are given continuity of quality care while transitioning living situations.
- ii. Currently, the subgroup is attempting to find ways to measure quality of life and well-being. The next meeting will focus on assessing best practices used by other organizations.
- iii. Mr. Gamache emphasized the need to work with other subgroups to ensure that there is not a complete overlap in duties. Lt. Governor Roberts replied that while there will inevitably be overlap in the

subgroups, they are taking on the issues from different points of views, which is favorable.

e. Research Subgroup

- i. Dr. Peter Snyder, the chair of the subgroup, was not present, but Lindsay McAllister reported that there have been two meetings so far. The first was a discussion of recruitment efforts across the state.
- ii. The second meeting was centered on the goals and jurisdiction of the subgroup. Currently, it is using the National Alzheimer's Plan as a guideline. The focus of the subgroup is to look at the intersection of care delivery and research (i.e. how new research and best practices can be disseminated to caregivers). There was also discussion about the potential of increasing recruitment of families to do Alzheimer's-related research.
- iii. At the end of the second meeting, Dr. Snyder sent out the National Plan and Vermont Plan to the subgroup members to have them tailor the research sections to Rhode Island's needs. It will be discussed at the next meeting. Please email Lindsay McAllister if you would like an electronic copy of those plans to edit.

f. Legal Subgroup

- i. Tom Enright reported that the subgroup focuses on the intersection of the legal rights of patients and the interests of the community. Some of the main categories of focus are dealing with issues of public awareness, elder abuse (physical and financial), and DMV policy changes. In particular, the subgroup is inviting police officers to the next meeting to discuss the possibility of training the police force to properly respond to cases of elder wandering.
- ii. The subcommittee members were given the task of researching existing best practices. They are also to look at the existing statutes in Rhode Island as they relate to drivers licenses and guardianship.
- iii. Someone from URI brought up the question of consent and at what point in the patient's disease does the caregiver override the wishes of the person affected with Alzheimer's or dementia. This is important to gaining legitimate consent for research purposes. The research and long-term care subgroups have also brought up the issue of consent.

4. Rhode Island Geriatric Education Center at URI: Dr. Philip Clark, Director of RIGEC presented.

- a. RIGEC developed out of the need to train the workforce to deal with the aging baby boomer population. The shifting demographics have a profound impact on Rhode Island because it has the highest percentage of elders over 85 in its population of the nation. The need for geriatric care will become larger and many primary care physicians right now do not have any training in geriatrics.
- b. RIGEC operates under an interdisciplinary structure across the state and has many organizations associated with it.

- c. Currently, it is funded by HRSA and it uses the grants to put on the Certificate Program as well as its annual Alzheimer's conference. The certificate programs run on a per-semester basis.
 - d. Lt. Governor Roberts asked whether there is a strengthening partnership between Brown and URI. Dr. Clark responded that while they have collaborated in the past, it is not an everyday endeavor. Someone in attendance mentioned the possibility of creating intra-professional training – beginning with the student level in the classroom.
5. **Alzheimer's Association of RI:** Donna McGowan, Executive Director for the Alzheimer's Association of Rhode Island
- The Rhode Island chapter was founded in 1989 from the national association. Currently, the chapter is sustained by donations, contributions, and grants. Its staff of seven offers free services (e.g. help lines, resource library, and caregiver support groups).
 - Currently, it implements a 'Live and Learn' program, which is a first-stage memory program (two hours in length). It is implemented in five sites across the state and gives caregivers some time off while the adults with the disease are able to create a community of support.
 - Additional programs implemented by the Alzheimer's Association are the Safe Return program for wandering patients, caregiver support groups, and brown bag lunches that raise awareness about warning signs for Alzheimer's.
 - A video was produced by the Alzheimer's Association and screened after the presentation.
6. **Administrative Items**
- a. Upcoming Listening Sessions - Lindsay McAllister mentioned at the prior meetings that there is a desire to open up the planning process for the state plan to the public. These Listening Sessions are open to the public and in addition to updating the public on the state plan, they are also a chance for the subgroups to hear personal stories about the challenges of caregiving.
 - i. The listening sessions will potentially be facilitated by community liaisons to create a trusting space. Please email Lindsay if you have suggestions for community facilitators. Also, please spread the word through different community organizations you are a part of.
 - b. National Alzheimer's Awareness Month (November) - The Rhode Island Alzheimer's Association will present a lecture on November 8th with Dr. Ott. It is free and open to the public. The Reason to Hope Luncheon will happen on November 28th at the convention center. It is a business luncheon that brings in people who are not familiar with the Alzheimer's Association and acquaints them with what the organization accomplishes.
7. **Meeting Adjourned** - The next meeting will take place on December 13th at Casey Family Services.